Tools for Communication

Novel infrastructure to address patient-perceived gaps in oncology care

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BACKGROUND: Healthcare providers (HCPs) and patient communication are integral to high-quality oncology care. The patient and HCP perspectives are needed to identify gaps in care and develop communication tools.

OBJECTIVES: This study aimed to understand patient- and HCP-perceived elements of and gaps in high-quality care to develop novel communication tools to improve care.

METHODS: Qualitative interviews were conducted among 16 patients with cancer and 10 HCPs in the United States. Trained interviewers elicited patients’ and HCPs’ concerns, views, and perceived needs for communication tools. A thematic analysis was used to identify four quality of care domains, depicted in a conceptual model, and two draft communication tools were developed to address identified gaps.

FINDINGS: No patients reported previously using a communication tool, and gaps in communication regarding treatment aims and education were evident. Two tools were developed to assess patients’ life and treatment goals and the importance of ongoing education.

HIGH-QUALITY PATIENT-FOCUSED CARE IS A KEY PRIORITY in oncology care. Improving quality of care can reduce suffering and improve quality of life (QOL) and survival (American Society of Clinical Oncology [ASCO], 2006). Traditionally, the evaluation of quality of care has been based on administrative data and has focused predominantly on clinical processes and outcomes as the primary quality metrics (Agency for Healthcare Research and Quality, 2016; ASCO Institute for Quality, 2017). Few quality indicators have assessed the patient's experience of care or have been developed with patient input. Meaningful quality indicators from patient perspectives should help guide care decisions, inform payment models, and act as incentives for providers in Accountable Care Organizations (ASCO, 2013; Spinks et al., 2011).

In 2013, the Institute of Medicine examined challenges and identified opportunities for improvement in the delivery of high-quality cancer care in the United States. Key recommendations focused on the need for healthcare providers (HCPs) to increase patient engagement, communicate personalized information to patients, and provide care in line with patient needs, values, and preferences (Institute of Medicine, 2013). The engagement of patients helps HCPs to identify the most important elements of high-quality care to patients, which may differ from those of HCPs. Previous studies have revealed that patients’ concerns regarding quality care differ from HCPs’ concerns and include communication at the time of diagnosis, patient involvement in treatment decisions throughout care (Teno, Lima, & Lyons, 2009), and QOL (Nguyen et al., 2011, 2014).

Effective communication between HCPs and their patients has been linked to improved patient satisfaction and perceptions of care quality, improved diagnostic accuracy, and increased treatment adherence (Institute for Healthcare Communication, 2011). This further supports the need for patient-focused quality initiatives that improve communication between HCPs and patients, which have proven useful in other healthcare disciplines. For example, in obstetrics, birthing plans have been proven to be valuable tools for education and communication by enabling patient preferences to be incorporated into treatment plans and by focusing care on issues identified as most important to patients (Aragon et al., 2013). Communication between patients and HCPs during the development of care plans helps ensure that
the interests of both parties are met and understood (Walling et al., 2015).

Many tools currently available within oncology are specific to an individual cancer type and, therefore, are not applicable to all patients with cancer (e.g., A Checklist for Patients With Breast Cancer [Blue Cross Blue Shield of Georgia, 2005], Personal Patient Profile—Prostate [Berry et al., 2010]). Others are specific to a niche topic (e.g., the comprehensive score for financial toxicity tool [de Souza et al., 2014], the Cancer Insurance Checklist [Cancer Insurance Checklist Partnership, 2017]), to one aspect of care (e.g., ASCO’s advance care planning [ASCO, 2015], survivorship plans [Journey Forward, 2017]), or intended for a cancer program rather than for patients (e.g., the Centers for Disease Control and Prevention’s [2012] cancer plan self-assessment tool, the Patient Navigation in Cancer Care Tool Kit [Patient Navigation in Cancer Care, 2008]). As current tools primarily target a specific audience, eliciting the patient perspective on the need for novel tools applicable to all patients from the time of diagnosis throughout their care is necessary. In addition, whether the currently available tools are being used in the workplace is unclear.

The objective of this study was to define quality care in oncology from the perspective of patients and HCPs, identify where gaps currently exist in the delivery of oncology care, determine if current communication tools are being used in real-world settings to address patient needs, and assess HCP and patient perspectives on what types of tools would be useful. The need for novel, more broadly applicable communications tools was identified in this study. Therefore, a secondary objective was undertaken—to develop patient-focused communication tools to address gaps in oncology care by incorporating important concepts for delivering quality care.

Methods
This cross-sectional study employed qualitative methods to elicit patient and HCP perspectives on high-quality care and assess the need for communication tools to improve the delivery of high-quality care. Based on these findings, in consultation with physicians and patient advocates, the current authors developed draft tools to address identified gaps in care.

Participant Recruitment
Eligible patients had a current or previous diagnosis of a solid tumor or hematologic cancer of any stage, had received chemotherapy or biologics for cancer treatment in the United States, were aged 19 years or older, were U.S. residents, and were willing and able to provide informed consent. Eligible HCPs were licensed nurses and physicians currently managing patients with cancer in the United States, played lead roles throughout patients’ treatment courses, and were willing and able to provide informed consent.

The protocol for patient interviews was submitted for ethical review and approved by Schulman Institutional Review Board, and recruitment occurred through treatment-center and web-based community boards. HCPs were recruited from a database of U.S. healthcare professionals who had consented to participate in qualitative research.

Qualitative Interview Process
Two rounds of qualitative interviews were conducted, and all interviews lasted about one hour. In the first round of interviews, concept elicitation interviews were conducted in person with eight patients and over the telephone with 10 HCPs (four oncologists and six nurses). Interviews were participant-led and conducted by trained interviewers using an interview guide with open-ended questions. Through the concept elicitation interviews, the authors aimed to identify important themes to patients and HCPs related to cancer management and treatment. These themes and concepts were summarized in a conceptual model of key elements of quality care developed by the authors. The interviews also aimed to understand if and how current communication tools were used, and to identify key gaps in care that could be addressed through communication tools. Patients and HCPs were asked to provide suggestions or ideas for tools that could improve quality of care. These suggestions were categorized into tool aims.

In the second round, trained interviewers conducted interviews in person with an additional eight patients using a structured interview guide. The aims of this round were to validate the importance of the items and concepts that formed the conceptual model and to identify the content for novel communication tools. In addition, these interviews were conducted to understand preferences for a new tool to address the gaps and needs identified by the conceptual model. Seven suggestions for aims of hypothetical tools, taken from the results of round 1 of the qualitative interviews, were presented to the patients: (a) educate patients, (b) assess patient understanding, (c) assess patient satisfaction, (d) brainstorm relevant questions, (e) connect with resources, (f) use a symptom tracker, and (g) assess treatment goals. Patients were asked to rate their preference for each tool aim on a scale of 1 (most preferred aim) to 7 (least preferred aim) and to rate their perceived usefulness of the tool aims on a scale of 1 (not useful) to 5 (very useful). For all rounds of interviews, a data saturation grid was maintained to determine when data saturation was achieved or if additional interviews were required.

Analysis
A content analysis of interview transcripts was conducted to classify the topics specific to the delivery or receipt of quality oncology care. Overarching themes that emerged from this analysis were classified as domains, and within these domains were more concrete issues or ideas termed concepts, which were based on
FIGURE 1. CONCEPTUAL MODEL OF THE KEY ELEMENTS OF QUALITY CARE FROM PATIENT, NURSE, AND ONCOLOGIST PERSPECTIVES

**Domain:** Communication
- Central coordinator of care
- Healthcare provider demeanor
- Time for discussion and thought
- Communication among healthcare providers
- Assessing satisfaction of patients
- Consistent voice
- Patient-directed
- Assessing understanding

**Domain:** Patient-centered care
- Understanding changing needs/choices
- Involving patient in decision process
- Patient needs, goals, and expectations
- Open-minded, flexible care
- Providing options and informing TX decisions

**Domain:** Quality of care
- Patient comfort, compliance, and prevention
- QOL
- Assessing understanding
- Providing options
- Informing TX decisions

**Domain:** Patient education
- Noncancer medical needs
- Availability of resources
- Psychological and emotional support
- Prevention
- QOL

**Domain:** Comprehensive care
- Social worker
- Physiotherapy
- Occupational therapy
- Survivorship care planning
- Financial
- Yoga and meditation
- Support groups

**Concepts:**
- Empathy/compassion
- Personable
- Humility
- Hopeful, reducing fear
- Accessible
- Non–matter-of-fact approach
- Assessing satisfaction of patients
- Consistent voice
- Patient-directed
- Assessing understanding

**Items:**
- Literacy/language
- Communication preferences
- Written/audio formats
- Ensuring comprehension
- Encouraging questions
- Knowing questions to ask

**Items:**
- TX and clinical trials
- Alternative medicine
- TX options
- Procedure options
- Appointment

**Items:**
- Pain management
- TX effect on daily/social life
- Other cancer
- Cancer type, stage, mutations
- Cancer prognosis
- Comorbidities
- TX differences
- Adverse events and TX complications
- TX duration
- TX impact on person, QOL

**Items:**
- TX difference
- TX efficacy
- Long-term impacts
- Fertility
- TX impact on cognition
- Adjuvant therapy
- Procedure details
- Recovery process
- Written/audio formats
- Ensuring comprehension
- Encouraging questions
- Knowing questions to ask

**Items:**
- Sexuality
- Impact on family and children
- Psychological/emotional needs
- Work
- End of life
- Spirituality
- Maintaining normalcy
- Diet and nutrition
- Exercise
- Comorbidities
- Social worker
- Family counseling
- Sexuality
- Impact on family and children
- Psychological/emotional needs
- Work
- End of life
- Spirituality
- Maintaining normalcy
- Diet and nutrition
- Exercise
- Comorbidities

TX—treatment; QOL—quality of life

Note. Bold items indicate difficult or rarely discussed topics, and some items appear in multiple domains.
specific items discussed during the interviews. The relationship between the domains, concepts, and items was illustrated in a conceptual model (see Figure 1). Suggestions for ways to improve quality of care from round 1 of interviews were summarized and presented to patients as seven tool aims in round 2. Feedback on tool designs was tabulated according to the patient rating and mean perceived usefulness of each tool aim.

Development of the Draft Tool
The results from the qualitative interviews informed the decision to develop novel patient tools to improve the quality of oncology care. Gaps identified from the patient and HCP interviews revealed a need for communication tools, particularly tools to communicate educational needs and treatment goals. Feedback from patient and HCP participants in both rounds of qualitative interviews was used to select the aim, format, and structure of each tool. The conceptual model was the basis for the communication tool content.

Feedback on the draft tools was solicited from one oncologist who specializes in palliative care and three executives from national nonprofit oncology patient advocacy organizations. All four have extensive experience in quality care initiatives specific to oncology.

Results
Participant Characteristics
Data saturation was obtained among 8 patients and 10 HCPs in the round 1 interviews and 8 patients in the round 2 interviews. The majority of patients were female with a mean age of 51.5 years (round 1) and 46.6 years (round 2), and with a mean age at diagnosis of 45.9 years (round 1) and 41.6 years (round 2) (see Table 1). Breast and colon cancer were the most common types of cancer among all patients interviewed, followed by lymphoma, lung cancer, and ovarian cancer. The stage of cancer at the time of diagnosis varied across study participants. All patients reported having never used a communication tool prior to initiating treatment. In round 1, three patients had no dependents aged 18 years or younger, two had one dependent, one had two dependents, one had three dependents, and one had four or more dependents. In round 2, five patients had no dependents aged 18 years or younger, and three had one dependent.

Among the 10 HCPs interviewed, the six nurses had a mean of 15 years of experience in oncology. The HCPs were equally split between community- and hospital-based practices. The four oncologists had a mean of 8.5 years of experience, and they spent the majority of their professional time treating patients (see Table 2).

Round 1: Concept Elicitation Interviews
The concept elicitation interviews revealed the key components of high-quality care from patient perspectives. Information saturation was achieved following 8 interviews, and round 1 interviews were stopped. The content analysis of the interview transcripts revealed 49 items, classified into 21 concepts, related to 4 overarching domains: communication, patient-centered care,
patient education, and comprehensive care, as depicted in the conceptual model.

More than 70% of the patients and HCP participants indicated that the potential side effects of treatment, ways of managing side effects, the impact of cancer and treatment on QOL and daily activities, and emotional support and needs were important educational topics. The effects of treatment on family and children and post-treatment concerns were important topics to patients but were not mentioned by physicians. Patients indicated that nurses were an important source of information and education. Educational items related to comprehensive care, such as financial options, sexuality, and family, were discussed infrequently by patients and HCPs and were often idiosyncratic based on each patient’s situation, suggesting a need for patients to communicate relevant educational topics to their healthcare team, because patient education needs differ from HCP needs and often include nontreatment-specific topics.

Patients and HCPs discussed different concepts related to communication. Most patients mentioned trust and honesty and the need for more or all information, whereas few HCPs mentioned these issues. Patients reported that physicians’ perspectives were barriers to communication, because they were focused on treating and eradicating the disease as opposed to treating the patient as a whole. This led to some of the important emotional, social, and logistical issues patients identified as absent from their conversations with physicians, indicating a need to ensure that patient and HCP goals are aligned before and during treatment, and for improved knowledge transfer between HCPs.

Round 2: Concept Validation and Tool Rating Exercise
The second round of qualitative interviews validated the concepts identified in round 1 and provided further understanding of the most important concepts to patients. The aspects of communication and patient-centered care most important to patients included clearly explained treatment options, having enough time to discuss topics of concern, patient-led decision making, having an open-minded care team, and the ability to change their mind. Patients expressed similar views regarding important topics for education in rounds 1 and 2. Treatment outcomes and the impact of treatment on QOL were identified as two very important educational items to patients when making treatment decisions. Many topics, particularly nontreatment-specific topics (e.g., pain management, understanding test results, emotional support), became more important to patients during treatment. Patients were also asked about their use of comprehensive care resources to help address these topics. Yoga, specialists, dietitians, and support groups were the most commonly used comprehensive care resources, whereas occupational therapy and family counseling were the least commonly used. Some patients were not familiar with certain resources or did not understand their purpose.

Table 2.

HEALTHCARE PROVIDER CHARACTERISTICS

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>NURSES (N = 6)</th>
<th>PHYSICIANS (N = 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S. region of practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>East Coast</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>West Coast</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>South</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Number of patients with cancer seen per month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–100</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>101–200</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>201 or more</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Manage patients prior to treatment</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>–</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Practice type</td>
<td></td>
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</tr>
<tr>
<td>Community</td>
<td>3</td>
<td>–</td>
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<tr>
<td>Hospital</td>
<td>3</td>
<td>–</td>
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<tr>
<td>Time spent treating patients (%)</td>
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</tr>
<tr>
<td>51–75</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>76–100</td>
<td>–</td>
<td>2</td>
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</table>
Elicit patient perspectives, which differ from those of HCPs and may change during the course of treatment.

Discussion

Research and clinical practice has increasingly focused on improving oncology care through the measurement of quality indicators and the implementation of novel quality initiatives. When developing meaningful quality initiatives, researchers and HCPs should consider the perspectives of multiple stakeholders, such as patients and nurses, to ensure the development of a comprehensive definition of quality care. As healthcare systems increase constraints on provider time and costly interventions, valid quality-of-care measurements may become important tools to help guarantee the provision of patient-centered care.

In the current study, patients and HCPs identified a number of common factors as key requirements for high-quality care, categorized into four domains: education, comprehensive care, communication, and patient-centered care. Patients and HCPs noted the overwhelming amount of information presented to patients and the need for ongoing education and assessment of understanding. Differences in educational priorities among patients and HCPs highlighted the importance of enabling patients to communicate their educational needs with their HCPs and the need for communication among HCPs regarding topics discussed with the patient. Although QOL factors were highly important to patients, they reported minimal use of resources that can help improve them. Many HCPs indicated that information on such resources is discussed only when a need arises, demonstrating an opportunity to improve the delivery of comprehensive care to prospectively diminish QOL effects. Assessing patient satisfaction and ensuring patient-specific communication were identified as key ways to improve communication. In addition, patient needs and life as well as treatment goals and expectations were reported to change over time, emphasizing the need for ongoing communication. Last, weaknesses in knowledge transfer between nurses and physicians were noted, resulting in inefficiencies in time

<table>
<thead>
<tr>
<th>TOOL AIM</th>
<th>RATING</th>
<th>USEFULNESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess patient understanding</td>
<td>1</td>
<td>4.9</td>
</tr>
<tr>
<td>Symptom tracker</td>
<td>2</td>
<td>4.9</td>
</tr>
<tr>
<td>Assess treatment goals</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Patient education</td>
<td>4</td>
<td>4.6</td>
</tr>
<tr>
<td>Brainstorm relevant questions</td>
<td>5</td>
<td>4.6</td>
</tr>
<tr>
<td>Assess patient satisfaction</td>
<td>6</td>
<td>4.5</td>
</tr>
<tr>
<td>Connect with resources</td>
<td>7</td>
<td>4.9</td>
</tr>
</tbody>
</table>

Note. Patients were asked to rate their preference for each tool aim on a scale of 1 (most preferred aim) to 7 (least preferred aim) and to rate their perceived usefulness of the tool aims on a scale of 1 (not useful) to 5 (very useful). The authors calculated the mean of the usefulness scores.

Draft Tool

The results from the qualitative interviews revealed gaps in oncology care. Patients reported a desire for improved communication with their care team regarding treatment goals and expectations and the need for improved comprehensive care specific to patient needs. No HCPs or patients in this study reported using tools to facilitate this communication but expressed a strong interest in having such tools.

A search of published and grey literature was conducted to identify oncology tools that are available for use and to determine if current tools could be used to address these gaps. The focus was on broadly applicable tools rather than disease- or treatment-specific tools, to ensure they could be used among a larger target population, with greater potential for improving quality care. No available tool for a broad target population addressed these specific gaps. The rating exercise was reviewed to determine which aims to address. The aims (a) assess patient understanding, (b) assess treatment goals, (c) patient education, and (d) brainstorming questions were aligned closely with the identified gaps in the qualitative interviews and were highly rated by patients. “Symptom tracker” was a highly rated tool; however, the authors determined that a symptom tracker may be of better use in cancer-type specific tools than in a broadly applicable tool. Tool 1 (see Figure 2) aims to facilitate a discussion of treatment expectations and goals, addressing the third-rated tool aim. This tool was designed to be completed by both patients and HCPs prior to treatment and revised throughout treatment as goals and/or treatment plans evolve and change. Tool 2 (see Figure 3) is a comprehensive education tool (e.g., it includes QOL items) that enables HCPs to assess patient understanding and continuing education needs, and helps patients brainstorm questions or concerns at the beginning of care, addressing three of the proposed aims. Both tools may improve the quality of time HCPs and patients spend together as well as inform nurses and physicians about what discussions have already occurred with the patient.

TABLE 3. PATIENT RATING AND MEAN USEFULNESS OF HYPOTHETICAL COMMUNICATION TOOLS

<table>
<thead>
<tr>
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<th>USEFULNESS</th>
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<tbody>
<tr>
<td>Assess patient understanding</td>
<td>1</td>
<td>4.9</td>
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<tr>
<td>Symptom tracker</td>
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<tr>
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<td>4.6</td>
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<tr>
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<tr>
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<tr>
<td>Assess patient satisfaction</td>
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<td>4.5</td>
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<tr>
<td>Connect with resources</td>
<td>7</td>
<td>4.9</td>
</tr>
</tbody>
</table>
spent with patients and the potential for missing important discussion points. The overlapping nature of the concepts and items within the four domains, as depicted in the conceptual model, illustrates that the construct of quality care is multifaceted and that diverse approaches can be taken to measure and improve quality of care.

The domains identified in this study were supported by previous research of patient perspectives regarding oncology care.

**FIGURE 2.**
**TOOL 1: PATIENT AND PHYSICIAN COMMUNICATION GUIDE FOR ASSESSING TREATMENT GOALS**

**PATIENT INSTRUCTIONS**
This tool was developed to help facilitate conversation between you and your oncologist or other members of your healthcare team in the treatment of your cancer. The aim of the tool is to help start conversations about long- and short-term goals, and to ensure that you and your care team both are in agreement. Please complete questions 1–4 of this form and share them with your doctor. Please revisit this form throughout your treatment to update any goals that may have changed, and discuss whether your goals are being met with your doctor.

**PHYSICIAN INSTRUCTIONS**
This tool was developed to help facilitate conversation between you and your patient about long- and short-term goals, to ensure you are both in agreement, and to help set expectations. Please complete questions 1 and 2 of this form, and then discuss any differences in goals between you and your patient to decide how to align them. Please revisit this form periodically with your patient to see if goals have changed and if the treatment plan is meeting these goals.

**QUESTIONS**

1. What are your long-term treatment goals (e.g., cure, maintaining quality of life, reducing specific long-term side effects)?

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>HEALTHCARE PROVIDERS</th>
<th>SHARED UNDERSTANDING</th>
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<tbody>
<tr>
<td></td>
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</table>

2. What are your short-term goals (e.g., ability to care for children, ability to work, maintaining specific activities)?

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>HEALTHCARE PROVIDERS</th>
<th>SHARED UNDERSTANDING</th>
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3. What, if any, are important events or life goals in your future that you want to attend or achieve (e.g., events that may occur during treatment, such as weddings, graduations, and vacations)?

<table>
<thead>
<tr>
<th>EVENT OR GOAL</th>
<th>TIME FRAME</th>
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</table>

4. What is your preference for decision making regarding your treatment and care?
   - [ ] I want to be very involved and be the primary decision maker.
   - [ ] I want to be fairly involved, sharing in the decision making.
   - [ ] I don’t want to be very involved, allowing my doctor to be the primary decision maker.
   - [ ] I want to include my family, friends(s), or other support system in the decision-making process. Please specify individuals and the role you would like them to have:
   - [ ] Other, please specify: ____________________________
**FIGURE 3.**
**TOOL 2: PATIENT EDUCATION TOOL FOR ASSESSING UNDERSTANDING AND NEEDS**

**INSTRUCTIONS**
This tool aims to help assess what specific topics you need more information on throughout your treatment course. Please complete this table before treatment and then again during treatment by checking the boxes to indicate that the topics have been discussed or that you would like more information. Please also write down any additional questions you may have and discuss them with your doctor at your next visit.

<table>
<thead>
<tr>
<th>TOPIC TO DISCUSS</th>
<th>BEFORE TREATMENT</th>
<th>DURING TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DISCUSSED WITH CARE TEAM</td>
<td>MORE INFORMATION DESIRED</td>
</tr>
<tr>
<td>Clinical trial participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet/nutrition</td>
<td></td>
<td></td>
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<tr>
<td>Difficulty following recommended treatment plans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of treatment</td>
<td></td>
<td></td>
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<tr>
<td>Emotional needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>End-of-life concerns or preferences</td>
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<tr>
<td>Exercise</td>
<td></td>
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<tr>
<td>Fertility concerns</td>
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<tr>
<td>Finances</td>
<td></td>
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<tr>
<td>Impact of treatment on daily activities (i.e., shopping, running errands)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of treatment on your ability to care for your family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of treatment on your ability to think clearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of treatment on your ability to work</td>
<td></td>
<td></td>
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<tr>
<td>Impact of treatment on your family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of treatment on your overall quality of life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of treatment on your social life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involvement of a support system in care</td>
<td></td>
<td></td>
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<tr>
<td>Logistics regarding appointments or treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long-term impacts of treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management of side effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other health problems</td>
<td></td>
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</tbody>
</table>

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## FIGURE 3. (CONTINUED)

**TOOL 2: PATIENT EDUCATION TOOL FOR ASSESSING UNDERSTANDING AND NEEDS**

<table>
<thead>
<tr>
<th>TOPIC TO DISCUSS</th>
<th>BEFORE TREATMENT</th>
<th>DURING TREATMENT</th>
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(Balogh et al., 2011; Fiscella et al., 2011; Gagliardi, Lemieux-Charles, Brown, Sullivan, & Goel, 2008; Ganz, 2002; Hess & Pohl, 2013; Kamal, Gradison, Maguire, Taylor, & Abernethy, 2014; Mallinger, Griggs, & Shields, 2005; Nguyen et al., 2011, 2014). The current study adds further understanding of patients’ opinions regarding education before and during treatment as well as their use and knowledge of resources and support services, topics that have been only briefly explored (Balogh et al., 2011; Fiscella et al., 2011; Hassett et al., 2014; National Coalition for Cancer Survivorship, 2001). Previous relevant conceptual models have been derived without patient input or have focused on specific aspects of quality of care, such as QOL or accessibility (Lavdaniti & Tsitsis, 2015; Mandelblatt, Yabroff, & Kerner, 1999). The conceptual model developed from the current study’s findings provides a comprehensive illustration of the components of quality care, combining patient and HCP perspectives.

The findings highlight the importance of communication between patients and HCPs, particularly around the time of diagnosis, and treatment decisions when a large amount of education is required and treatment expectations are being set. These are ongoing needs, and strong patient and HCP communication can ensure continuing education and address changing needs. Studies in the United States have revealed that patients’ assessment of care is heavily influenced by their communication with and trust in their physicians and by receiving care that is responsive to their personal preferences (Common Wealth Fund, 2002; Institute for Healthcare Communication, 2011; Lis, Rodeghier, & Gupta, 2009). This also highlights the need for HCPs to initiate communication around care planning at the beginning of care. The use of tools to facilitate discussions between patients and HCPs has been found to be beneficial in other areas of health care (Aragon et al., 2013; Whitford et al., 2014). Previous assessments of birthing plans have showed that patients’ feelings of choice and control were strongly related to their overall experience (Cook & Loomis, 2012). The qualitative interviews in the current study revealed similar results; the patients’ overall experience of care was highly correlated to their perceived treatment choices, control, and relationships with their HCPs.

Most of the current tools in oncology, however, are limited in their widespread application, as they focus on specific patient populations or stages of cancer treatment (Berry et al., 2010; Blue Cross Blue Shield of Georgia, 2005; Cancer Insurance Checklist Partnership, 2017; de Souza et al., 2014) and tend to be used later in the disease process to help with advanced care or survivorship planning (Kamal et al., 2011; Journey Forward, 2017). In the current study, patients did not report experience using communication tools, and HCPs indicated that they were not part of their routine practice. However, all patients expressed interest in communication tools, recognizing their role in improving quality of care. A literature review conducted by the current authors did not identify a current tool with a broad target population that helped patients and HCPs communicate treatment
expectations and education needs. Although such a tool may exist, it is not readily identifiable in the public domain and is not being routinely used in cancer care in the United States. Based on this need, two draft tools were developed for all patients with cancer for future validation. The first tool helps HCPs elicit patient goals and desires around treatment and communicate with that one another, which can improve patient-centered care and communication between members of the healthcare team. The second tool helps nurses gauge patient education needs, which may increase the effectiveness of time spent with patients and the meaningfulness of the interactions to patients.

In this study, feedback was elicited from both patients and HCPs, enabling an evaluation of differences in perspectives. Patients had diverse cancer types and received various treatments from multiple providers over numerous years; therefore, each patient could speak to various experiences of care. Furthermore, the draft tools were developed with feedback from clinical advisors and patient advocates familiar with available oncology tools and the challenges of using such tools in clinical practice.

Limitations

The results of this study were subject to limitations, primarily the generalizability of results. The HCPs were actively involved in quality improvement initiatives; therefore, they may not be representative of the general provider population or provide the type of care received by all patients. In addition, a small patient sample was used, and many of them were recruited from the same practice or support group, increasing the likelihood of similar experiences and demographic characteristics; as a result, concepts that are important to other patients were not identified. Future studies are warranted to validate and pilot test the tools with a larger patient sample and in various practice settings to help refine the tools and expand their generalizability.

Conclusion

This study identified strong communication, patient-centered care, comprehensive care, and ongoing education as integral components of quality care in oncology from the patient and HCP perspectives. A need for novel tools that focus on these domains was identified. The findings of this study informed the development of two draft tools that focus on the most important domains of care to patients and aim to address unmet needs of patients with cancer in the United States. These tools can be used by nurses in oncology care to improve communication between patients and their entire care team.

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REFERENCES


